ALERT

News from the UFMCC
on AIDS Legislation, Education, Research and Treatment.

JANUARY, 1989

MCC-DC PASTORS HIRED AS CONSULTANTS AT CATHOLIC U.

Rev. Larry Uhrig, Pastor, and Rev. Candace Shultis, Associate Pastor of the Metropolitan Community Church of Washington, D.C. have been hired to serve as Pastoral Care Consultants to a major AIDS research project being funded by a National Institute of Health grant. The project is called, "Coping Response in HIV Infection: A Panel Analysis." It is a study of the long-term nursing care needs of persons with HIV, and is being conducted by the School of Nursing of The Catholic University of America.

The grant was awarded by the NIH to Dr. Mary Elizabeth O'Brien, Faculty Member and Director of the Doctoral Program at the Catholic University of America School of Nursing. The $379,000 grant covers activity from November, 1988 to October, 1991.

Dr. O'Brien originally came to MCC-DC in April, 1988, to hear Rev. Steve Pieters, UFMCC Field Representative for AIDS Ministry. In subsequent worship experiences with MCC-DC, she recognized Uhrig's and Shultis's unique pastoral care ability and experience with AIDS, and approached the pastors with the invitation to join the panel.

Rev. Uhrig stated, "It is significant that we were sought out for this: this creates a linkage between the Catholic University and MCC, and will give us an opportunity to serve as a resource to other components of the Nursing School."

ADVANCED IMMUNE DISCOVERIES SYMPOSIUM, 1989

An "International Professional Conference and Public Forum for Immune Solutions" will be held at the Registry Hotel at Universal City in Los Angeles, CA, February 4, 1989. Billed as an "up-to-date broad educational experience for both the public and health care professionals," the symposium will feature over 50 presenters discussing AIDS-related topics ranging from Long-term Survivors to "New and Unusual Protocols" and "Non-Toxic and Drugless Therapies."

Among the presenters will be George F. Solomon, M.D., author of the study of psychosocial and immune aspects of long-term survival, "Psychoneuro-immunology and HIV Infection."

For more information, or to register, write: World Health Promotions, 2210 Wilshire Blvd., Suite 650, Santa Monica, CA 90403 or call (213) 394-3073.

AIDS: DEFYING THE ODDS CONFERENCE IN D.C.

The "First International Conference on the Traditional and Complementary Therapies in the Prevention and Treatment of AIDS" will be held at the Mayflower Hotel in Washington, D.C., February 17-19, 1989.

The Conference, called, "AIDS: Defying the Odds: Living Long and Living Well, A Case for Optimism," will feature leading experts in "both traditional and complementary areas of medicine to talk about drug therapy, progress toward a vaccine, guided imagery, acupuncture, nutrition, life style, and more." Long-term survivors' personal stories will also be featured.

Bernard S. Siegel, M.D., author of Love, Medicine, and Miracles, will be a featured speaker, and in a pre-conference fundraising dinner, will share the podium with Elizabeth Kubler-Ross.

For further information and registration, write or call: The Institute for Learning Mastery, P.O. Box 314, Baltimore, MD 21203; (301) 366-7373.

MINISTRY RESOURCES AVAILABLE

"Ministry Resources in Response to AIDS", compiled by The Rev. Jeffrey Pulling, Ph.D., and updated for January, 1989, is available from Church Services Dept., c/o UFMCC, 5300 Santa Monica Blvd., Ste 304, Los Angeles, CA 90029.

The list of resources includes all UFMCC AIDS Ministry Resources, as well as recommended books, pamphlets, and packets from a variety of denominations, as well as a review by Rev. Pulling of an issue of Religious Education devoted to AIDS.

CENTER FOR DISEASE CONTROL (CDC) NATIONAL AIDS HOTLINES

1-800-342-AIDS -- English
1-800-344-SIDA -- Spanish

THE FORMING OF "GRAIN"

Recently representatives from various faith communities/ traditions in Rochester, New York have come together to form GRAIN - Greater Rochester AIDS Interfaith Network. Impetus for the formation of GRAIN came as a result of Rochester's first AIDS Vigil of Prayer (Feb. 1988) co-sponsored by Open Arms Metropolitan Community Church and AIDS Rochester, Inc. Two interfaith services were held with the Most Reverend Bishop Matthew Clark (Roman Catholic) bringing the message at the Friday healing service, and the Right Reverend Bishop William Burrill (Episcopal) speaking at the Saturday memorial service. Over two hundred persons braved freezing weather to attend each service.

Several individuals discussed formation of such a group with the Reverend Cathy Elliott, pastor of Open Arms Metropolitan Community Church following the AIDS Vigil of Prayer. She indicated the belief that someone from a mainstream denomination should provide the initial leadership to diffuse the focus of AIDS as a gay issue. When the Reverend Paul Walker (Episcopal) discussed the formation of a group with Reverend Elliott, she gladly supported him and committed herself to the development of it. Reverend Elliott is serving as vice-convenor of GRAIN.

GRAIN's Mission Statement spells out its "prophetic task":

> "As people of faith, we strive to assure that all those whose lives are affected by AIDS/HIV infection will receive compassionate non-judgmental respect, care, support and assistance. AIDS is not divine punishment. God's merciful, loving and empowering presence is with all affected by disease, including AIDS/HIV infection...We serve God and humanity by striving to emulate divine compassion, to seek justice, and to provide service."

GRAIN is seeking affiliation with the AIDS National Interfaith Network.

[ENCLOSED FOR YOUR CONVENIENCE IS AN OFFERING ENVELOPE FOR THE UFMCC AIDS MINISTRY. THANK YOU FOR YOUR SUPPORT]

IN BRIEF
FROM THE AIDS/HIV RECORD

(Vol. 2, No. 19, Nov. 15, 1988)

* In a study from the Centers for Disease Controls (CDC), Dr. Jonathan Kaplan and colleagues have suggested "that the risk for AIDS increases after the third year of Lymphadenopathy Syndrome (LAS)." Reported in the Nov. 15 AIDS/HIV Record, the study followed 75 Gay men since 1982 and 1983. The cumulative incidence of "full-blown AIDS" increased in the fourth through sixth years after development of LAS. LAS is a generalized swelling of the lymph glands, often associated with HIV infection.

* The American Foundation for AIDS RESEARCH (AmFAR) has announced grants totalling $190,000 for AIDS education. The Minority AIDS Project in Los Angeles and the Multi-Cultural Training Resource Center in San Francisco will each receive $20,000 to develop innovative education programs, and $75,000 has been granted to both the National Urban Coalition of Washington, D.C. and the Southern Christian Leadership Conference of Women in Atlanta, GA to further their education efforts.

Dr. Mervyn Silverman, President of AmFAR, was quoted in the AIDS/HIV Record as saying, "More than 40% of people with AIDS in the US are now minorities. Much needs to be done to educate people in communities of color about the dangers of AIDS, and the fact that the disease continues to spread at an alarming rate. AmFAR's goal is to provide support to outstanding groups in the affected communities to take the lead in developing innovative programs to halt the spread of AIDS."

* High incidence of stroke among PWA's: Neurologists at the University of California, San Francisco, report that strokes are 30 times more frequent among AIDS patients than among people of the same age group in the general population. John W. Engstrom, M.D., is quoted in the AIDS/HIV Record, "The message for doctors is, if you see a young person with a stroke of unknown cause, you have to consider a diagnosis of AIDS. A quick diagnosis is crucial, because in as many as half the cases the cause of the stroke may be treatable." The causes of stroke in persons with AIDS ranged from Kaposi's Sarcoma lesions on the brain to clots that had travelled from the heart. The most common infections among this patient population were cryptococcal meningitis and toxoplasmosis, although herpes zoster and tuberculosis were also noticed in some patients.

* NAPWA Honors Windom: The National Association of People with AIDS (NAPWA) recently honored Assistant Secretary for Health, Robert E. Windom. Steve Beck, NAPWA Executive Director, was quoted in the AIDS/HIV Record, "While the efforts of Surgeon General Koop in the area of prevention and education are well known and extremely important, only a very few people understand that Dr. Windom has taken on the formidable task of getting the American public and corporations to be compassionate and lend a helping hand to people with AIDS."

"SURVIVING & THRIVING"
VOL II, NOW AVAILABLE

People With AIDS Coalition of New York just released "Surviving and Thriving With AIDS Volume Two-Collected Wisdom", a 368 page book of writing by people with Acquired Immune Deficiency Syndrome. It also contains many photographs of people with AIDS.

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Surviving & Thriving...(Continued)

The Coalition also announced that "Surviving and Thriving With AIDS: Hints for the Newly Diagnosed", published in Summer, 1987, will be reprinted for the second time. Twenty thousand copies have been distributed. Both books are offered free to people with AIDS and ARC.

"The two books are meant to be read together, and in order," according to Michael Callen, editor of both volumes. "Hints is still essential reading for the newly diagnosed. Collected Wisdom expands upon the information and ideas contained in Hints. It's an anthology of our attempts to cope with AIDS. It's a slice of lives which captures what it is like to live with AIDS in America in the late '80s."

Volume Two contains a large section on treatment options. AZT, aerosol pentamidine, DHPG, TPN, AL721, and holistic approaches are discussed in first-hand accounts. Volume Two also attempts to remedy what Callen views as the major deficiency of Hints - that it contained little material not generated by white, gay men. The new book contains much material by and about women and AIDS and people of color with AIDS. It also includes a section about AIDS-Related Complex and HIV antibody positivity.

The general public may purchase either book by mail order from: PWA Coalition, 31 West 26th Street, New York, NY 10010 or call (212) 532-0290. Volume Two costs $20, Volume One (Hints) $10. Bulk rates are also available.

CDC CREATES TWO MINORITY POSITIONS

(Reprinted with permission from: NAN Multi-Cultural NOTES on AIDS Education and Service; Vol 2, No 2)

The Centers for Disease Control (CDC) has created two new positions to deal with issues of minority health. The first, Assistant Director for Minority Health, has been filled by Reuben Warren, a dentist with additional degrees in public health (master's and doctorate), who most recently was Dean of the Dental School of Meharry Medical College in Nashville Tennessee. Dr. Warren joined the CDC staff August 8, in order to provide him an opportunity to attend the second CDC minority conference August 15-17 in Washington, which attracted 2,000 minority-related service providers from community-based AIDS agencies among others.

"Primarily, my responsibility is to assess, advise, coordinate and evaluate minority health activities and interface with Prevention and Surveillance of Preventable Diseases and Conditions," Warren said. "This position afforded me an opportunity to get in at the service level where I perceive the action to be."

The second position, which Dr. Warren asserts was created in response to recommendations made by participants at the August conference, is that of Special Assistant to the Deputy Director (AIDS) for Minority Activities. That position is temporarily being filled by Dr. Helene Gayle, who has served at the CDC for four and a half years, most recently as a medical epidemiologist for the AIDS program, specializing in pediatric and family HIV studies. A search is currently underway to fill the position permanently. Gayle said the position is threefold, coordinating minority AIDS activities within the CDC, between the CDC and other branches of the Public Health Service, and in partnership with groups outside the Department of Health and Human Services.

NEW CONTROLLED CLINICAL TRIAL INITIATED

The Food and Drug Administration announced today that Syntex Corporation and the National Institute of Allergy and Infectious Diseases are initiating a controlled clinical trial of Syntex's investigational drug, ganciclovir, in AIDS patients with cytomegalovirus (CMV) retinitis, an eye infection that can lead to blindness.

CMV retinitis occurs in patients whose immune systems are compromised, such as recipients of organ and bone marrow transplants and persons with AIDS. The new study will include all patients with newly diagnosed AIDS-related CMV retinitis that is not immediately sight-threatening, estimated to be about 20 patients a month.

Those patients with immediately sight-threatening CMV retinitis will be eligible for treatment with ganciclovir under a new Treatment IND sponsored by NIAID. The Treatment IND was approved by FDA under its recently revised regulations, which make available promising drugs that are still under study to patients with severe or life-threatening diseases.

For several years, Syntex Corporation has been supplying ganciclovir to AIDS patients and others on a compassionate use basis. The company will continue to furnish the drug, free of charge, to all patients who are currently receiving the drug under compassionate use.

FDA Commissioner Frank Young, M.D., said, "I am very pleased that, working together, Syntex, NIAID, and the FDA have designed a framework that will meet the needs of all patients who may benefit from treatment with ganciclovir." He explained that the controlled clinical trial will answer the question of whether ganciclovir effectively arrests or prevents the progression of sight-threatening retinitis.

"Regardless of geographic location, all eligible, newly diagnosed patients can participate in the controlled clinical trials or the Treatment IND," said NIAID Director Anthony S. Fauci, M.D. Any physician in the U.S. may enroll a patient in the controlled trial or the Treatment IND. Some patients may be treated through NIAID's nationwide network of AIDS Clinical Trials Units.

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New Clinical Trial...(Continued)

The patients with non-sight-threatening CMV retinitis will be randomized into one of two treatment groups in the controlled trial. One group will begin immediate treatment with intravenous ganciclovir and the other group will receive delayed treatment. All patients will be closely monitored for any changes in their clinical condition. At the first sign of worsening disease, patients in the delayed treatment group will be offered ganciclovir and monitored for response.

Study participants who have been taking zidovudine (AZT), the only approved anti-AIDS drug, must discontinue AZT when they begin treatment with ganciclovir. Because both drugs are toxic to white blood cells, AZT and ganciclovir cannot safely be taken simultaneously.

Physicians and patients interested in either the controlled trial or the Treatment IND may call the Ganciclovir Study Center at (301) 497-9888.

ALPHA INTERFERON APPROVED FOR KS; OFFICIAL DOSE TOO HIGH?
(By John S. James)

(Reprinted with permission from AIDS Treatment News, Issue Number 70, December 1, 1988)

On November 21 the Food and Drug Administration (FDA) approved use of alpha interferon to treat KS.

The drug, already available by prescription since June 1986 and previously approved to treat hairy cell leukemia and genital warts, is being marketed under two brand names, Intron-A (Schering Corp.) and Roferon (Hoffman-LaRoche). The two versions have slightly different molecular structures.

After the FDA approval, AIDS TREATMENT NEWS talked with Mathilde Krim, Ph.D., founding chairperson of the American Foundation for AIDS Research (AmFAR). While best known for her work with AmFAR, Dr. Krim is also a leading expert on interferon. In 1975 she became co-director and then director of an interferon laboratory at Memorial Sloan-Kettering Cancer Center in New York, a position she held until 1985 when she left to do AIDS work.

Dr. Krim is concerned that the doses on which the FDA based its approval may be much too high. Two weeks ago, at an international meeting on interferon research in Japan, Dr. Ernest Borden showed that as long as the dose was enough to produce the desired effect, a higher dose made little difference; this result was based on human as well as test-tube work. Other researchers, including Dr. Clifford Lane and colleagues, who used high dose interferon and published an article in The Lancet (November 26, 1988), showed that those who responded well usually started with over 150 T-helper cells, while those who did not respond had fewer. The important factor seemed to be the state of the immune system, not the dose.

Also, clinical studies with the high doses, 20 million units a day or more, caused such unpleasant flu-like side effects that in order to keep the patients in the study, physicians had to reduce the dose to half or a quarter. Yet the beneficial effects continued.

Dr. Krim also noted that much smaller doses have been found effective in treating hairy cell leukemia, in some cases as little as one and a half million units given twice a week.

But the early studies of alpha interferon for KS had used large doses, because the dominant thinking, derived from chemotherapy, was that the dose should be as high as the patient could tolerate. The FDA had to use the data available, much of it from early studies, as the basis for the approval. This may give patients and physicians the impression that they need high doses. But these doses cause unpleasant side effects, and also are very expensive, conceivably costing as much as $50,000 in a year.

Dr. Krim believes that alpha interferon would probably be effective at much lower doses, and would be well worth trying.

10 NEW AIDS DRUG DISCOVERY GROUPS AWARDED

The National Institute of Allergy and Infectious Diseases (NIAID) has awarded $6.4 million for 10 new National Cooperative Drug Discovery Groups for AIDS (NCDDG-AIDS) bringing to 28 the total number of groups funded. "The Drug Discovery Groups have already shown extraordinary promise in providing a firm scientific framework for targeted drug discovery for AIDS. Expanding the program will ensure continued contributions to expedite discovery of drugs effective against AIDS," said Dr. Anthony Fauci, NIAID Director.

The NCDDG-AIDS program began in 1986 with five research groups, and added 13 groups in 1987. Each group is funded for 3 or 5 years. NCDDG-AIDS funding for fiscal year 1988 was $18.2 million. Each group is composed of three to seven senior scientists from academia, industry, or government, who are experts from diverse scientific disciplines. Members of each group apply their research skills toward the discovery, creation, and development of new and better therapies for AIDS.

Each Drug Discovery Group has independently chosen a rational drug design strategy and is also doing random drug screening. Because of their independent appraoches, directions taken by the groups are extremely diverse. Some groups focus on deciphering the AIDS virus structure and mechanisms of replication to design drugs that interfere with the building of new viral particles. Other groups test the ability of natural substances--such as from trees or marine organisms--to suppress the AIDS virus or to stimulate the immune system. Still others make chemical compounds synthetically that may stop the virus or stimulate the body's defenses to fight the infection.

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